TENNESSEE GENERAL ASSEMBLY FISCAL REVIEW COMMITTEE



FISCAL NOTE

SB 2084 - HB 2362

February 11, 2016

SUMMARY OF BILL: Creates the Access to Pediatric Rare Disease Treatment Information Act. In order to participate, an institution must provide a written statement of participation to the Commissioner of Health and post such statement either on a public-access website or be forwarded by the institution in writing to every hospital in this state that has in excess of one hundred beds and provides inpatient care to patients under eighteen years of age. A participating institution must maintain all essential treatment information with respect to patients admitted for care after January 1, 2017, or following issuance of a statement of participation, whichever is earlier. "Essential treatment information" includes all treatment information pertaining to patients who are under 18 years of age at the time they are diagnosed with any form of cancer, including, but not limited to, leukemia (all types), glioma, lymphoma, medulloblastoma, neuroblastoma, osteosarcoma, sarcoma, and Wilms tumor.

If a participating institution, upon receipt of a participation request from another participating institution, cannot timely fulfill the participation request, it shall provide the requesting institution, within 10 days of the original request, either a statement of variance or a statement of incapacity. Statements of variance must state the date on which the participating institution can fulfill the participation request, not to exceed 60 days, and state the reason that the participating institution requires more than 10 days to fulfill the participation request. A statement of incapacity must state that the participating institution cannot fulfill the participation request in whole or in part. Requires statements of incapacity and the participation requests to which such statements of incapacity are directed, as well as minutes of the advisory board, with any appendices, be provided, within sixty days from the date the statement of incapacity was sent to the participating institution making the participation request, to the Commissioner of Health and the Division of Records Management of the Department of State.

Creates an advisory board to be made up of two members to be selected by St. Jude Children's Research Hospital, two members selected by the Monroe Carell, Jr. Children's Hospital at Vanderbilt, one board member selected by each additional participating institution in the state, two members selected by the Governor, the Commissioner of Health, and each of Tennessee's appointees to the National Conference of Commissioners on Uniform State Laws. Such members will not be compensated nor reimbursed for any expenses incurred for attending meetings of the board.

ESTIMATED FISCAL IMPACT:

NOT SIGNIFICANT

SB 2084 - HB 2362

Assumptions:

- The Commissioner of Health would be a non-voting member of the advisory committee. Members of the advisory board will not be compensated nor receive reimbursement for expenses incurred.
- There is no oversight required by the *Act*; therefore, it is estimated that there will be no significant fiscal impact to the Department of Health.

CERTIFICATION:

The information contained herein is true and correct to the best of my knowledge.

Krista M. Lee, Executive Director

rista M. Lee

/jem